Using Atlas CareMaps to strengthen families and communities

Sparking Transformative Conversations

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Atlas of Caregiving is a Silicon Valley-based nonprofit conducting research on family caregiving and developing tools (like Atlas CareMaps) to help families better understand their own situations. We’re making visible the invisible world and manage of family care so that all those striving to support and improve family wellbeing have a better foundation for their efforts.

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This book is for you if you care about:

• the health and wellbeing of your community (whether you think of them as your employees, neighbors, citizens, members, or patients), and/or

• strengthening the sense of community, and improving community resiliency.

You will learn about Atlas CareMaps — a tool and process for understanding family care ecosystems — that not only helps families better care for themselves, but also creates a foundation for community-wide initiatives. It helps people see their interconnectedness, how they each contribute to community wellbeing. It sparks social conversations that in turn unleash community wisdom.

If you want to take action, this book provides a primer on nurturing organic adoption of Atlas CareMaps.

To see additional and latest information about Atlas CareMaps, you can visit www.atlasofcaregiving.com/caremap/.
Late one evening in Santa Barbara, California, Betty spoke of her family’s caregiving situation with a bright smile and no shortage of laughter.

Two months earlier her mood had been very different. She had drawn her first Atlas CareMap (basically a drawing of a family’s care ecosystem, showing who supports whom and how). As she shared her map with others, she broke down in tears, explaining how overwhelmed and alone she felt caring for an aging parent, while also managing her business and being a good mother and wife.

That night she realized that she could not be “Super Betty”, and that allowing others to help did not mean that she was a negligent mother or wife. At home, she shared her map with her husband and children, and asked for them to do more. They readily agreed, and her life changed dramatically.

Inspired, Betty taught her employees how to draw their own Atlas CareMaps and reflect on their own lives. She coached them on how to speak to their husbands and relatives, to help them overcome the same cultural expectations that had held her back. She did the same with her relatives. The ripples caused by Betty’s learning Atlas CareMaps continued to spread.

All the participants in that earlier workshop were volunteers with Promotores de Salud, an organization devoted to improving the health and wellbeing of Santa Barbara’s Latino community. All had similar stories. The particular circumstances varied, but all had learned something valuable, and many told stories about teaching others.

The experience had also changed their relationships with each other. Before the workshop, they would not have spoken with each other about their personal family care situations. Caring was just not a normal topic of social conversation. After, it became natural. When they met each other at a store or at some event, they would ask “What’s changed in your CareMap?” Through these conversations, they are sharing practical tips and feeling more supported.

The Promotores have gone on to hold CareMap Workshops for their community, tailoring the material to their community’s characteristics. They also began to use Atlas CareMaps in all sorts of human care situations, beyond caring for a very sick person. For example, people feeling alone — single parents, pregnant teenagers, even a young boy whose parents had been deported — to help them see the community of people who cared about them and were actively involved in their wellbeing.

The ripples continue.
About Atlas of Caregiving

Atlas of Caregiving is a Silicon Valley-based nonprofit conducting ground-breaking research on family caregiving and developing tools (like Atlas CareMaps) to help families better understand their own situations. We’re making visible the invisible world of family care so that all those striving to support and improve family wellbeing have better information on which to base their efforts.

Atlas of Caregiving sprang from the findings of a 2014 expert roundtable on family caregiving. People from a wide variety of organizations — healthcare institutions (Kaiser Permanente, Veterans Administration, and the US Dept. of Health and Human Services), foundations (Robert Wood Johnson Foundation, California HealthCare Foundation), nonprofits (National Alliance for Caregiving, Family Caregiver Alliance, United Hospital Fund), businesses (Intel, GE/CareInnovations), and several experts in design, community, work-life issues, and media — discussed what was known about the state of family caregiving, and what could be done to accelerate innovation.

The roundtable’s report Catalyzing Technology to Support Family Caregiving1 highlighted key opportunities and challenges. A major outcome of the roundtable was the group’s acknowledgement of the dearth of data about family caregiving. While some good research had been conducted, far more was unknown. It seemed unlikely that major innovations could occur without a better understanding of families’ situations and challenges. But, how could richer data be gathered?

The Atlas of Caregiving Pilot Study was an experiment to see whether it was possible to collect much more detailed data about day-to-day, even minute-to-minute family caregiving through the development of novel research methods combining traditional anthropology and modern technologies. Supported by the Robert Wood Johnson Foundation, and carried out in 2015-2016, the Pilot used these novel methods to study 14 families, with a wide variety of circumstances and health issues.

The project demonstrated that it was possible to collect detailed data, and that this data provided dramatic new insights into the actual, lived realities of family caregiving. The results were published online and in a report2.

Following the success of the Pilot Study, to continue the work Atlas of Caregiving was formally incorporated as a non-profit in 2016. Since then, Atlas of Caregiving has continued to develop and improve methods for gathering and analyzing data about family caregiving, and to disseminate our learnings through public speaking and publications. We also develop, teach and disseminate tools, like Atlas CareMaps, that individuals can use to understand and manage their own lives.

During 2017 and 2018, the Santa Barbara Foundation and AARP were major collaborators. The Mapping Santa Barbara3 project focused on exploring the impact of Atlas CareMaps, and examined other self-study tools.

[1] The report can be downloaded at: https://atlasofcaregiving.com/research/
[2] Interactive presentations of the 14 case studies and a downloadable report can be found here: https://atlasofcaregiving.com/pilot-study/
What is an Atlas CareMap?

The Atlas CareMap is a drawing and a process for self-reflection and action, which also provides a catalyst for conversation.

A Drawing

Most obviously, an Atlas CareMap is a drawing of your family’s care ecosystem, showing who is supporting whom, and how. The drawing has “Actors” (people, pets, professionals, and places, shown using different symbols), and “Links” (arrows that connect the Actors showing who actively provides support for whom, with different types of lines indicating how frequently the support is provided). Your placement of Actors corresponds roughly to where they live.

The drawing itself has value. It helps you more clearly see your own situation, and to describe your situation to others. Others seem to respect the drawing more than a verbal-only description of the same situation (more “data” and less “anecdote”).

You can draw Atlas CareMaps by hand or using a webapp (AtlasCareMap.org). I strongly suggest you first learn to draw by hand.

An example: Christi’s hand-drawn Atlas CareMap (top) shows the many caring relations that exist within her family, who are spread out in different parts of the US. In Princeton, NJ, Christi and Mike support his mother Maria, who has dementia and lives next door. Several other relatives and professionals also support Maria. Christi and Mike also support a son, Pablo, who has diabetes. Mike and his brother Steve (in Philadelphia) also support his father Arturo (in Baltimore), while Christi and her sister Janet support her parents Eileen and Jim (in Orlando). Two nearby friends and a local support group provide support to Christi and Mike.

A webapp-created Atlas CareMap (bottom) includes more details. For example, different colored Links indicate different types of support (e.g., the School Nurse provides medical support to Pablo, while Ruth provides emotional support to Christi). The webapp also includes additional functionality, such as for different views of the current situation and for seeing changes over time.
A Process for Self-Reflection and Action

The process of drawing, and then reflecting on what has been drawn, has proven to be a powerful tool for deeper understanding of one’s situation. Thinking about the questions that need answering to draw the map — such as: Who provides care support to whom in your ecosystem? What are the different types of support provided? Who is deeply involved and who is not and why? — gives clarity, and often new perspectives, to the situation.

Clarity comes over time. You will likely have a new perspective immediately after drawing an Atlas CareMap for the first time (often simply because you haven’t given deep thought to your ecosystem before). The drawing and insights will stay in your mind, and as you continue to think about those questions and their answers and see the world through a new lens, your perspectives may shift again. You might find it useful to redraw your map, either literally or just in your mind, as you gain more clarity. And since life doesn’t stay still, you may want to redraw your map as the situation changes.

Once you have clarity, what do you do? That depends … people’s circumstances vary widely, so there is no definitive “next step”. However, as general statements, many have found that an Atlas CareMap helps them plan for potential difficulties, manage the many people involved, identify missing people and services, and communicate with everyone. In addition, the Atlas CareMap often helps people appreciate what is working well.

To Care is Human (this includes you)

Caring for others, especially our closest relatives and friends, is a fundamental human activity. Almost everyone, except for the very young and the very frail, contributes to the wellbeing of at least few people. And almost everyone is supported by others throughout their lives. This is not only during times of limitations imposed by illness, injury, or disabilities, but also in regular life. We are social animals — everyone in your community already contributes to somebody’s wellbeing and is supported by someone.

Therefore, everyone can find value in drawing their Atlas CareMaps and better understanding their care ecosystem. So, if you are reading this book, appreciate that the Atlas CareMap is for you. Before you act on this book’s recommendations, if you have not already drawn your own map, read the Atlas of Caregiving’s publication See the Invisible: Strengthening your care ecosystem with Atlas CareMaps and draw one for yourself. You will find it at www.atlasofcaregiving.com/caremap/.

A Tool for Sparking Transformative Conversations

People often find great value in sharing their maps with relatives and friends. Showing and talking about your Atlas CareMap opens the door to conversations that lead to understanding, appreciation, and support. Those you speak with will often open up about their perspectives on your situation (as depicted by the map you share), as well as about their own situations. Empathy is generated and knowledge is shared. It may lead to them wanting to draw their own Atlas CareMaps, and you can show them how to do it.

In our experience, once multiple people in a group have drawn and learned from their own maps, there is a transformative change in group conversations about care. People discover they have so much to gain, emotionally and practically, from sharing their care experiences and knowledge.
Designing Organic Adoption

The image of a ripple on a pond is an apt metaphor for community-wide adoption and use of Atlas CareMaps. Two key ingredients are CareMap Workshops (the pebbles that start the ripples) and person-to-person conversation (the continuing ripples).

Well-designed and taught CareMap Workshops, as detailed a little later, leave participants with new insights about their own personal situation, a deep understanding of the power and usefulness of Atlas CareMaps, and new skills and comfort in speaking with others about care.

As Workshop participants continue to interact after the Workshop (because they are work colleagues, members of some social group, or friends), the conversation begun at the Workshop continues. The question “What’s changed on your CareMap?”, becomes commonplace.

This — social conversations about care becoming commonplace — is very important. It results in people more fully leveraging the resources of the community, sharing ideas and support, and becoming less reliant on professionals and institutions.

In certain situations, such conversations can lead, and have led, to profound changes in the community. We think of this as “unleashing community wisdom,” and it provides a foundation for community action.

Here are some suggestions for introducing Atlas CareMaps in your community. The intent is to catalyze organic community learning by sparking multiple conversations. CareMap Workshops are the pebbles that start the change. Multiple workshops, intentionally held with a diverse set of community segments, starts the process.

Begin with leaders and influencers

Do not try to reach “caregivers”. This is a trap. Instead, recognizing that everyone is likely caring for someone, begin by introducing Atlas CareMaps to the leaders in your community, to those who are most active and engaged in the issues. If you are part of some organization, start with your board, executives, staff, key volunteers, etc.

Once they have experienced a CareMap Workshop, once they have found some value in examining their personal care ecosystem, information about Atlas CareMaps can spread organically, as people talk about their maps with their relatives and friends. You (all) will also be in a better position to determine who to reach out to next in your community.
Tailor as needed

Once you have some experience with Atlas CareMaps, you will likely have some ideas about how to tailor CareMap Workshops for your community. For example, you may teach initially using the Atlas CareMap examples found in our Seeing the Invisible booklet. But you will likely want to quickly replace them with examples that will be more relatable to your community: different names, different locations, different health conditions, different family configurations, different types of services, etc.

Create a conducive environment & Unleash community wisdom

As noted earlier, CareMap Workshops spark social conversation about care, which can result in unleashing community wisdom, as people tap into deep knowledge held by the community (currently untapped due to the lack of social conversation). There is much you can do to create an environment conducive to social conversation about care.

Lead by example, and have those leaders and influencers, the first local participants in CareMap Workshops, tell their stories publicly. Through the Workshop, using the Atlas CareMap, they have learned how to describe their caring situations. Do this publicly, to show everyone how to do it, and that it is okay to do this. Support local venues for such story telling, whether through local media, local arts organizations, or other community organizations.

Recognize such social conversations, and celebrate examples of people learning from each other and supporting one another. Today professional efforts are widely reported and recognized, while the community’s own efforts are hidden. Change this and unleash community wisdom.

Nurture organic adoption

While CareMap Workshops are a great way to introduce the concept into a community, direct person-to-person teaching may likely soon become the primary way people learn about it. In one survey, CareMap Workshop participants had each shared and/or taught Atlas CareMaps to 10 other people.

To intentionally nurture such organic adoption in your community, plant many good seeds by holding CareMap Workshops, led by high-quality Workshop teachers, for a wide variety of organizations in your community.
Leading CareMap Workshops

Since February 2016, hundreds of people have learned to draw and learn from their maps in CareMap Workshops led by Atlas of Caregiving. These two-hour workshops have been carefully designed to not only teach people the mechanics of drawing an Atlas CareMap, but to spark social conversation about care. We intentionally create an environment (through words, pacing, materials, physical space, and actions) that allows people to feel comfortable reflecting on their own lives and sharing their experiences. Participants get to experience the learning that results from conversations about care with other participants — better understanding their own situation from trying to describe it, and getting new insights by hearing about other people’s situations and their perspectives.

Almost everyone who has participated in a CareMap Workshop has learned a lot about themselves and their situations, and has been glad to have participated in the process (this even includes those who discovered how much more difficult their situation was than they had previously realized). For many the impact has been significant; for some it has been life-changing.

Atlas of Caregiving has taught others to lead CareMap Workshops. Such training is best done in person. But, if you would like to organize and lead such workshops yourself without such training, here we describe what we believe to be important for a great workshop:

**Structure of the Workshop**

Organize the two-hour workshop into four, roughly 30 minute, sections.

- First, introduce the concept of Atlas CareMaps and walk people through several examples (like those found in our *Seeing the Invisible* booklet).

- Second, lead participants step-by-step through drawing their own map, and then give them suggestions for reflecting upon their map.

- Third, break participants into small groups of 3-4 people, and have them show and describe their Atlas CareMaps to each other. (Note: this third section is key to the “magic” of the CareMap Workshop. People learn about their own situations in the process of describing it to others. People become aware of the value of social conversation from listening to and reflecting on the experiences of others.)

- Fourth, with everyone back together encourage participants to share personal discoveries and/or key topics from the small-group conversations, before closing the session with some final thoughts.

**Social conversation**

One of the most important aspects of CareMap Workshops is that they spark social conversation about care. People discover a way to talk about their care situations with others, gain confidence in doing so, and in the process experience the emotional and practical benefits of talking with others about care. The impact of this should not be underestimated. The challenge for the workshop instructors is to balance a goal of ensuring that all participants learn the material with a goal of encouraging peer-to-peer learning. Be too strict, minimizing conversation, and people don’t experience the value of social conversation. Be too lax, and the session can end up being no different than a regular caregiver support group.

**Rules for gentle listening**

It is very important to create an environment in which participants feel safe speaking about their personal family caregiving situations. Especially for the small-group conversations, when participants show and describe their maps, it is important to emphasize: listen respectfully; listen to understand the speaker’s perspectives don’t problem-solve, don’t judge, don’t criticize, and even don’t praise.

**Group size**

Successful CareMap Workshops have been conducted with just one participant and as many as 50 people. “Successful” in that the participants felt the Workshop was very valuable. However, in our experience, we have found that 12-20 people is an ideal size. With this many, there are likely to be enough people for some diversity in life-experience to contribute to a rich conversation. With more people, there will not be opportunity for everyone to speak up, and knowing this seems to lead to everyone being more reserved.

**Accept the discomfort**

Some people’s lives are hard; some people are very isolated. As such people describe their situations, especially during the small-group conversations, they may be overcome with emotion. This can be uncomfortable for that person, as well as other participants and the instructor. The response must not be: to ban such experiences from the Workshop (by not allowing such people to participate), to assuage such people that “it’s not so bad” or “it will all work out”, or to jump into problem-solving.
Experience more important than mastery

It is far more important that people experience the process of drawing and reflecting on their own Atlas CareMap, describing their map and situation to others, and hearing from others, than it is that people learn to draw their map “correctly”. If the experience was valuable, they can always re-learn the simple process of drawing Atlas CareMaps, and can always re-draw their map to be more accurate or neater.

Room layout

Ideally, seat participants at small tables of 3-4 people each. This way they are already set for the small group conversations. Tables are important, as a surface for drawing. If there are only chairs, the chairs should be placed in groups of 3-4, and clipboards provided for drawing.

Pens, not pencils

We have found it is much better to provide pens for drawing, rather than pencils. As pencil marks can be easily erased, participants seem to pressure themselves into erasing to create a “neat” map. With a pen, people seem resigned to messiness, and so worry about it less.

Don’t rush to act

We end our Workshops by gently discouraging people from acting with haste. Participants may have had significant “aha’s” during the Workshop, new insights into their situations that they may be eager to act upon. However, after the Workshop, seeing the world through new eyes, as they continue to reassess their situation, they may come to new, and different, insights. We remind people that learning, especially self-learning, doesn’t happen instantly, and so they should move with deliberation.

About privacy

People in Workshops will be sharing personal information with each other; this is inherent to the concept. We have taken four key steps to minimize potential privacy dangers.

• First, no one is pressured to say anything they don’t want to. What they draw on their map is up to them; what they share with the group is up to them. Not actively participating is okay (we’ve actually only had one participant who actively choose not to draw a map, but by the end of the workshop she opened up and we discovered a person who had experienced decades of hard and lonely caregiving but then was incredibly generous in sharing her wisdom).

• Second, the “rules for gentle listening” are key to people feeling comfortable, and being gentle with each other.

• Third, the amount of time each person is “on stage” is limited to a few minutes within the small-group conversation section of the Workshop, and they’re speaking to a small set of people, not to the whole group.

• Fourth, we do not collect people’s drawings. At the start, in early 2016, we took photos of people’s maps (with their permission) to assist our research, but we stopped doing that. Since then, we have only asked to take such photos on rare occasions, when people have done something innovative in their drawings.

When we have led CareMap Workshops for groups that work together (employees of some organization) we acknowledge the situation up front, noting that they may be unused to speaking about their personal lives with their colleagues. We gently ask them to think about the others in the room as fellow human beings, as friends and neighbors. In our experience, such Workshops have always ended with a great spirit, as participants seemed to find joy in just being human with their colleagues.

A final suggestion for CareMap Workshop leaders: do not be paternalistic about your participants’ privacy. Trust them to judge for themselves what they want to disclose, and trust them to treat what they learn about others in an appropriate way.
A Foundation for Community Action

Atlas CareMaps may prove to be a powerful tool for addressing a more fundamental societal issue than just family caregiving. The experience of the Promotores, of their self-directed use of these maps to help people feeling disconnected from society, shows how the Atlas CareMap can be used to build a foundation for healing and strengthening communities. We can leverage the ubiquity of family caregiving — instead of viewing it as a “crisis” we can view it as a source of strength. We can use Atlas CareMaps to spark conversations, helping people discover their common humanity. We can use Atlas CareMaps to help people see how interconnected their lives already are.

The importance of tools for building community.

More and more there is a sense that our communities (at all levels from the neighborhood to the nation to the world) are becoming increasingly fragmented. That individuals feel ever less a sense of connection, a sense of belonging. Though these trends are not new, the negative implications seem ever more serious. Many have noted that to improve society, we must begin by healing, rebuilding, and strengthening communities.

To strengthen communities we must first recognize the group. A recent article on the website of New America foundation was titled “Our Laser-Like Focus on Individualism Is Destroying Our Communities”. Fortunately there is growing appreciation of community. Luz Vega-Marquis, CEO of Marguerite Casey Foundation, writes “Today I don’t get as many stares as I once did when I talk about how families are the unit of change and the source of leadership our country needs.”

New York Times columnist David Brooks writes “It could be that the neighborhood, not the individual, is the essential unit of social change. ... Thinking in neighborhood terms requires a radical realignment in how you see power structures. Does the neighborhood control its own networks of care, or are there services providers coming down from above? ... Thinking in neighborhood terms means radical transformation in how change is done. It means escaping the tyranny of randomized controlled experiments in which one donor funds one program that tries to isolate one leverage point to have 'impact'”.

In Community: The Structure of Belonging, author Peter Block explains that a sense of belonging is fundamental to community. He notes that “belonging” has multiple facets: a person must feel that he belongs in the community, that he knows that others in the community also feel that he belongs in the community, and that the community belongs to him (a sense of ownership, of stewardship, of responsibility towards). Peter also deliberately uses the word “structure” to acknowledge that such a community doesn’t just happen, but is created intentionally, with effort and discipline and care. However, he also notes that more important than the formal structures of community are actual experiences of community. Our job as community builders is to create and nurture opportunities for experiencing community. He writes “The essential challenge is to transform the isolation and self-interest within our communities into connectedness and caring for the whole.” Building community is work, and tools are required. In the book Peter offers a set of Six Conversations, that together are a valuable tool.

Many others have developed useful community-building tools. The ABCD Institute (Asset-Based Community Development Institute), founded three decades ago by John McKnight and Jody Kretzmann, is based on their research that showed that local assets are the primary building blocks of sustainable community development. The “assets” are the skills, capacities, and interconnections of the individuals, associations, and organizations within the community. The Institute has created a large set of resources and tools to help communities identify and leverage their assets.

The Atlas CareMap is an important addition to the community-building toolbox. From our experience to-date, it can help in two complementary ways.

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4 Chayanne Polimédio, Our Laser-Like Focus on Individualism Is Destroying Our Communities, New America Weekly, Edition 220, Oct. 4, 2018
6 David Brooks, The Neighborhood is the Unit of Change, The New York Times, Oct. 18, 2018
7 https://resources.depaul.edu/abcd-institute
Atlas CareMaps to spark conversations

CareMap Workshops create opportunities for people to talk with one another, with respect and empathy.

Though caring for family is a fundamental, universal human activity, such caregiving is generally not a topic for normal social conversation. This absence of conversation has significant negative consequences, as people are deprived of the emotional and practical support such conversation could provide. How to stimulate such conversation and reap the benefits was described earlier in Designing Organic Adoption.

There is, however, a silver lining to today’s lack of social conversation about care. In today’s hyper-partisan, deeply-divided environment, family care is a rarity — a major but overlooked social issue, one without rigid partisan positions. Rich or poor, urban or rural, liberal or conservative, white or black (and every shade between) … all agree that caring for our own is both fundamental and difficult. CareMap Workshops provide an opportunity to bring together disparate people and help them discover their common humanity. It’s an opportunity to talk about something that doesn’t instantly put you in one camp or another. An opportunity to just talk, to listen and be heard, without the pressure to convince or defend or act.

Atlas CareMaps to recognize community.

Atlas CareMaps help people see their current, existing community. The effect starts small, with seeing the small ecosystem of relatives, friends, professionals, etc., that people include the first time they draw their Atlas CareMaps. But as this new way of seeing the world sinks in, people start seeing (and can be helped to see) the larger ecosystem that allows them to thrive.

We believe that the thought process sparked by examining our small ecosystem then slowly expands to see other, weaker-but-important ties with the larger community. We slowly become more aware of the ways in which we benefit from the presence of many others in our lives, the larger community within which we exist. Likewise, we begin to appreciate how we are contributing to the wellbeing of the larger community. We humans are social animals and as such we do care about others in our community, but for various reasons we have learned to hide this fact, even from ourselves. The Atlas CareMap can help us rediscover the truth.
A Brief History of Atlas CareMaps

2012 Summer Interns

Atlas CareMaps began modestly, as a small part of a summer internship project. The first diagrams were created in Summer 2012 by two college students working for me, to illustrate the caring relationships of families they had interviewed. We developed a design scheme to highlight relationships, distance, frequency of interaction, and types of support. I included these diagrams in conference presentations, discovered that people found that the diagrams helped them better understand the families I was describing, and began to appreciate that we had created something new and useful.

2015 Quantified Self Conference

At the June 2015 Quantified Self Conference in San Francisco, I chose to offer a workshop on “Self-tracking and family caregiving”. As part of the workshop, I taught people how to draw their own CareMap. Working with Dubberly Design Office, we improved the clarity and aesthetics of the 2012 design, and created a brief instructional guide.

2015 Atlas of Caregiving Pilot Study

Working with Dubberly Design Office on the Atlas of Caregiving Pilot Study, in the summer and fall of 2015 we explored many design variations and improvements to depict the care ecosystems of the families that participated in that research. We explored methods developed to depict computer networks, social networks, and family ecosystems (such as genograms) in search of useful ideas, but eventually concluded we had to develop our own design language.

2015 Hand-drawn Atlas CareMaps

As I presented preliminary results of the Atlas Pilot Study and showed the Study’s maps in Fall 2015, many asked how they could draw their own. It became increasingly clear that there was a need for instructions for drawing an Atlas CareMap by hand. I worked with Jon Cousins to define a process that was simple enough for anyone to do. The resulting method became the basis for what we teach today. In December 2015, we described the process in a blog post.

Through responses to the post, we became aware of other efforts to depict family care ecosystems, the most notable of which was by Cristin Lind. Exploring these other ideas helped us clarify what was different and valuable about our approach, as well as what was in a similar spirit.

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1 https://atlasofcaregiving.com/put-your-family-caregiving-on-the-map/
2 https://thejourneyetc.wordpress.com/2012/09/19/durga-tool-9-my-care-map-or-the-picture-that-tells-a-thousand-words/
2016 CareMap Workshops in Santa Barbara

The Atlas of Caregiving Pilot Project and the blog post caught the attention of the Santa Barbara Foundation, which had a major initiative focused on supporting local family caregivers. Conversations led to the idea of conducting an experiment — teaching people how to draw and learn from Atlas CareMaps through an in-person workshop (rather than from reading a blog post). A series of five such workshops were conducted in February 2016. There was a total of 80 participants, an even mix of health and social professionals (social workers, nurses, etc.) and regular people. The workshops were very successful. Everyone felt they learned something about themselves, that the Atlas CareMap was a powerful tool, and that they were glad they had participated. We were encouraged to hold many more workshops.

2017 Mapping Santa Barbara & AARP CareMap Workshops

The success of the experimental CareMap Workshops in February 2016, led to a major project in 2017 in Santa Barbara exploring the value of Atlas CareMaps called Mapping Santa Barbara. As people learned, used, and taught Atlas CareMaps, we confirmed that the concept was very valuable to individuals, families, and communities. In certain groups, Atlas CareMaps, and social conversations about caregiving sparked by the maps, became a part of day-to-day life. We also learned that many Workshop participants were inspired to teach others how to draw their own maps, and felt confident doing so. Local institutions started to incorporate Atlas CareMaps into their formal services. Inspired by the enthusiasm in Santa Barbara, AARP hosted CareMap Workshops in several cities across the country in 2017. The experiences of teaching hundreds of people how to draw and learn from Atlas CareMaps, seeing their maps, learning about their situations, and listening to their ideas, has refined the ideas and recommendations found in this book.

2017 Development of Atlas CareMap webapp

In early 2017, Atlas of Caregiving contracted with the leading information design firm Accurat to design and develop a webapp for creating Atlas CareMaps. Their own explorations of visualizing personal data and their spirit of data humanism resonated with our vision. The result was released to the public in January 2018.

2018 Exploring Community Impact

Struck by the profound impact of Atlas CareMaps on the Promotores volunteer organization in Santa Barbara, we began conversations with experts in community building, such as Peter Block and John McKnight. The section A Foundation for Community Action summarizes our findings.